Title: An Interactive Health Communication Program for Young Urban Adults with

Asthma

PI: Alan Baptist, M.D.

Team Members: Christine Joseph, Ph.D

Peter Song, Ph.D.

Organization: University of Michigan

Inclusive Dates of Project: 9/30/2012 to 9/29/2014 with NCX 3/31/2015

Federal Project Officer: Steve Bernstein

Acknowledgement of Agency Support:

The project described was supported by grant number 5-R21-HS-020977-02 and its contents are solely the responsibility of the authors and do not necessarily

represent the views of the Agency for Health Research and Quality.

Grant Number: 5-R21-HS-020977-02

Structured Abstract

Purpose: To understand the experiences and perspectives of young African American adults managing their asthma, and to develop a health IT program for this population

Scope: To date, little research has focused on optimal interventions in young African American adults with asthma.

Methods: Focus groups were conducted with 34 young African American adults with asthma. Next, the findings of these focus groups were used to develop a 6-week computerized health IT intervention based upon the principles of self-regulation. Finally, the health IT intervention was pilot-tested in a new sample of 44 participants. These participants were followed for 3 months.

Results: Important findings about the specific asthma management challenges for the target population were found in the focus groups. These findings were used to successfully develop the health IT intervention. When tested, the health IT intervention improved asthma quality of life and asthma control over a 3 month period. Retention rates over 80% were noted.

Key Words: Asthma; African American; health disparities; adolescent; young adult; asthma education; asthma self-management; health information technology; electronic; computer

Purpose

- 1. To determine the causes of poor asthma control in young adult African American patients, paying particular attention to the patient's perspective and preferences. We will accomplish this goal using focus groups.
- 2. To develop a consumer health informatics application for young adult asthma patients in urban areas. We will incorporate the information obtained in specific aim #1 with a self-regulation behavioral model of change. This program will be tailored and responsive to the needs of individual patients, and will empower them to take control of their asthma.
- 3. To pilot test the health informatics application as a way to improve asthma-specific outcomes. We will measure pre- and post- asthma specific outcomes (i.e. asthma control, asthma quality of life, medication use, health care utilization, and asthma self-efficacy), as well as collect process data regarding usability, usefulness, and needed improvements.

Scope

A1.0 Health disparities in asthma

Health disparities have been seen in many conditions, such as cancer, diabetes, and cardiovascular disease. One condition with a significant disparity in health outcomes is asthma. Recent prevalence rates for asthma in the United States demonstrate that 7.3% of the population has asthma, though this rate is 8.1% in African Americans. Although the prevalence rate is slightly higher, the severity and control measures are significantly worse. For example, the 2006 age-adjusted hospitalization rate among whites in Michigan was 10.6 per 10,000 people, whereas for blacks it was 45.9 per 10,000. This rate is nearly six times higher than the 'Healthy People 2010' target of 7.7/10,000. These disparities are also seen in urban areas such as Detroit, where the age adjusted hospitalization rate is 56.9/10,000 for blacks yet only 27.5 for whites.

Health disparities in asthma are due to both environmental and underlying genetic factors. Urban areas, which often have a predominance of African American patients, may have factors associated with asthma such as air pollution, cockroaches, dust mites, poor diet, poverty, stress, and violence. However, studies that have controlled for these factors find that African American individuals have an asthma prevalence that is 1.5 to 3 times higher than whites, significantly worse asthma outcomes, decreased visits with asthma specialists, and decreased use of an inhaled corticosteroid for persistent asthma.

Our group has an interest in determining the reasons for these poor asthma outcomes in minority populations. We recently completed a prospective study of 104 hospitalized urban adult asthma subjects (95% black) and found that self-efficacy is most strongly associated with both emergency department visits and hospitalizations in this urban population (Baptist et al, unpublished data). Other variables examined included asthma knowledge, attitudes towards asthma care, barriers to care, overall health, income, education, and availability of a primary care physician – yet none of these factors remained significant in a logistic regression model. Therefore, interventions that directly address self-efficacy will likely improve asthma outcomes.

A2.0 Attempts to decrease asthma health disparities

A variety of interventions have been employed to decrease health disparities in urban areas, with mixed results. Some of these include NIH funded network studies, such as National Cooperative Inner-City Asthma Study (NCICAS) and Asthma Control Evaluation (ACE). The NCICAS (utilizing education and environmental control in pediatric patients) was able to decrease asthma symptoms and hospitalizations, whereas the ACE trial (utilizing biomarkers to guide therapy in adolescent and young adults) was not effective at improving outcomes. Although other trials evaluating comprehensive asthma education and environmental control in urban environments have shown some benefit in young adults, one argument against more widespread implementation is difficulty in their real-world sustainability. Difficulties that must be overcome include obtaining funds for an asthma educator and/or social worker, achieving buy-in at multiple levels (departmental, organizational, and community), personnel turnover, and enrollment difficulties. Overcoming these difficulties is unfortunately not practical for many physicians or health care systems, who must also deal with lack of adequate reimbursement for services. A recent study evaluated the 'real world' ability to implement the NCICAS protocol in community settings, and found that only 24.8% of 4,174 children were able to complete the protocol.

A3.0 Health IT interventions to decrease asthma health disparities

One method that has been attempted to improve outcomes in the pediatric population is a health IT intervention utilizing computerized asthma education. Computerized education has the advantage of improved dissemination as the program can be administered remotely. There have been eight previous computerized asthma education programs delivered to pediatric patients, with mixed results. Most of these trials appeared to improve patient asthma knowledge but not objective clinical outcomes such as hospitalizations, acute care

visits, and lung function tests. One reason for the limited success of these programs is that they were not tailored to address the specific challenges an individual may face, which would more fully engage the user, nor did they address self-efficacy. Instead, they often provided standard education through a computerized format.

While our group and other have attempted to improve asthma health outcomes for urban children and teenagers with asthma through health information technology (IT), none have examined urban young adults. In fact, asthma is very understudied in urban young adults, who display health disparities just as severe as children. Although there have been eight computerized asthma education programs targeted towards children, there have only been 3 focused on adults. Two showed very minimal results, and the one that did improve outcomes was performed in the Netherlands, not in an urban black population. Importantly, this study from the Netherlands was performed with a health IT intervention based upon self-management and education.

Consumer health informatics is a branch of health IT that studies and implements methods of making information accessible to consumers. It also models and integrates consumers' preferences into medical information systems. A goal of consumer health informatics is to make medical knowledge more accessible to patients, thereby allowing them to become more vested in their care. For chronic medical conditions such as asthma, empowering patients to self-manage their disease is crucial.

A4.0 A tailored health IT intervention for adolescents

Rather than simply providing basic asthma information, our group developed the first tailored computerized asthma education program, Puff City (Tailored Asthma Management for Urban Teens 2R01HL068971, PI: Joseph) directed towards urban adolescents. In this high risk population, during a 1 year follow-up period we were able to reduce asthma symptoms (RR = 0.5, P = 0.003), school days missed (RR = 0.3, P = 0.006), restricted-activity days (RR = 0.5, P = 0.02), and hospitalizations for asthma (RR = 0.2, P = 0.01) when compared with control students. One reason why the Puff City intervention was successful whereas others were not is the fact that it was designed to be personalized, tailored, interactive, and developmentally appropriate. These features allowed delivery of asthma education and management skills to address relevant cultural, social, environmental, and psychological factors specific for each subject.

This study shows that a carefully developed and tailored program can have positive results. However, the specific messages used in Puff City would not be appropriate in a young adult population, as the challenges and obstacles differ from those seen in adolescents. In the current protocol, we will draw upon our experience from Puff City but will focus on the needs and priorities of young adults.

While the analysis of Puff City showed an overall improvement for the entire cohort compared to the placebo arm, we also had individuals who did not respond to the targeted interventions. The PI and Co-I (Joseph) on this grant have recently analyzed reasons for this. Two important factors associated with non-response in this high risk population included low baseline asthma self-regulation (OR = 4.7, p < 0.01) and low emotional support (OR = 6.6, p = 0.01). We will explore these factors in the current protocol through initial focus groups and, if verified, will incorporate the concepts into the final intervention.

A5.0 Asthma among young adults in urban settings

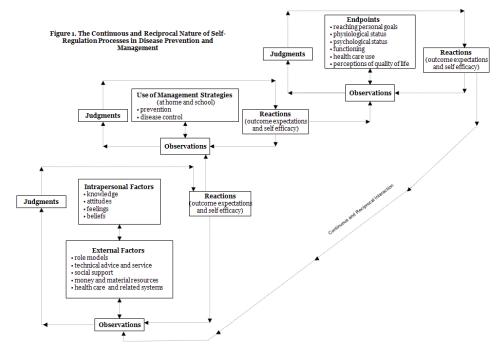
As noted above, our group has performed research directed at adolescents with asthma. However, young adults in an urban setting have not received adequate investigation. In fact, a 2009 survey of residents of Detroit and Michigan found that among adults, the prevalence rate of current asthma was highest among individuals age 18 - 24 at 12.7%, which was significantly higher than the overall current adult rate of 9.9%. In that survey, the prevalence rate of current asthma was higher in young adults age 18 - 24 than any other age group – including teenagers and children age 10 - 14.

Young adults in urban environments also have hospitalization rates much higher than the 'Healthy People 2010' goal of 7.7/10,000. In fact, young adult women in Michigan had a rate of 29.7/10,000 and young adult men had a rate of 18.8/10,000. Part of this reason may be that young adulthood represents a dramatic change for an individual, where for the first time they may be responsible for their own health care, finances, education, and employment responsibilities. Compounding this problem, many pediatricians stop caring for patients once they turn 18, and adult practitioners may not be fully trained nor equipped to deal with the challenges and personalities of young adults just out of adolescence.

A6.0 A self-regulation theoretical model for asthma

One approach to behavior modification is social cognitive theory, particularly using the principles of self-regulation with support. Social cognitive theory has been well-developed in the literature and has been used extensively to explain human health behavior. The core principles of the theory explain that there are multiple factors that interact to influence behavior. The most influential way in which a person develops these expectations and solidifies a behavioral change is through personal experience, which is defined in the theory as self-regulation. Zimmerman described self-regulation as a process of three phases: self-observation, self-judgment, and self-reaction, and Zimmerman and Clark (Co-I on this grant) adapted these sub-processes to asthma. Clark et al then developed a more refined self-regulation model that explicates the sub-processes and associates them with asthma outcomes (Figure 1). Through the self-regulatory process, the person is able to observe and learn from their experience and determine ways for changing behavior. This process has been shown to build confidence and strengthen the commitment to continuing the new behavior.

Our group completed the "Women Breath Free" study (Effect of Self-Regulatory Education on Women with Asthma, R18HL60884, PI: Clark), in which 808 women with diagnosed asthma were randomized either to receive an individualized program based on the Clark et al model of self-regulation or to a control group. Compared to the control group, the intervention group had greater annual reductions in average nights with asthma symptoms, days of missed work/school, emergency department visits, unscheduled office visits, and scheduled office visits. They also reported greater improvement in quality of life, self-regulation and self-confidence to manage asthma. In addition, our group has previously developed interventions for cardiac disease based on the proposed model of self-regulation, which also have shown multiple positive results. However, we have not previously attempted to enhance self-regulation of young adults through an IT platform. This proposal will provide the first theory-based and IT-delivered intervention for a highly vulnerable group of asthma patients through a medium that is increasingly accessible to, and valued by, the population.



A7.0 Health IT interventions in urban environments

A self-regulation intervention is ideally suited to be delivered electronically to urban populations. Use of an electronic delivery system allows the program to be personalized to the subject's time, interest, and priorities. A concern sometimes raised for use of a computerized intervention in urban populations is lack of computer access. However, recent estimates have shown that in urban areas with predominantly black populations, over 66% of young adults regularly use email or the Internet. Access to computers and the Internet continues to increase dramatically, and recent initiatives from the federal government allocating \$7.2 billion towards this effort will ensure that this trend will continue.

Our own data has also shown that urban black participants have a strong interest in health IT interventions to improve asthma. The PI for the proposed study recently completed a survey of 145 young adult and adolescent asthma subjects, evaluating the proclivity to use email, Internet, and social media in order to improve care of asthma (Baptist et. al. unpublished data). Twenty percent of the subjects were urban black asthma patients, and of these 67.9% stated they used email at least once per week, whereas 89.7% stated they used the Internet at least once per week. For the entire cohort, 59% of subjects responded that they had high or moderate interest in receiving asthma information through email, and 63% stated that they had a high or moderate interest in asking their physician asthma questions through email. Both of these figures were approximately double that for text messages and Facebook (at 34% and 22% respectively). Using logistic regression to identify factors associated with an interest in receiving information through email or text message, we found that nonwhite race was significant for both (OR = 2.8, p = 0.032; OR = 4.5, p = 0.007, respectively). Similarly, we found that nonwhite race was significantly associated with high/moderate use of text messaging to communicate with a physician about asthma (OR = 2.7, p = 0.030), and in the adolescent population nonwhite race was significantly associated with high/moderate use of email to communicate with a physician (OR = 10.9, p = 0.010). Taken together, these results indicate that email and Internet are the preferred health IT methods for receiving asthma information, and that African American participants may be more likely to respond to this technology.

Methods

The protocol was set up in two parts: focus groups and development/validation of the health IT intervention

FOCUS GROUPS

Subjects

Focus groups were conducted with 34 African American adults 18 to 30 years old with a physician diagnosis of persistent asthma. All participants were self-identified as African American. Persistent asthma was defined as currently using a controller medication (inhaled corticosteroids, inhaled corticosteroids plus long-acting b agonist, or a leukotriene modifier) on a daily basis, using a rescue medication at least 3 times per week, or having been to the emergency department in the past year because of asthma. Participants were ineligible if they had any other significant cardiopulmonary disease, had a greater than 20 pack-year smoking history (because this level has been associated with the development of chronic obstructive pulmonary disease); were not fluent in English, or had a significant cognitive impairment that would make participation in a focus group impossible.

Participants were recruited from the University of Michigan asthma registry and 2 community clinics. Most patients who were recruited using the University of Michigan asthma registry had some type of insurance. One of the community clinics is a federally qualified health center, which provides care for individuals without insurance. The other recruitment site is a community outreach clinic, which serves adolescents and young adults exclusively, often without insurance. Demographic information and responses to the Asthma Control Test were collected by a self-administered questionnaire. The University of Michigan institutional review board approved the study, and all participants provided written consent.

Focus Group Design and Data Collection

A research team composed of 2 asthma and allergy physician specialists and 2 behavioral research scientists with experience conducting asthma focus groups developed a series of open-ended questions and prompts to guide discussions. The questions were based on a review of the asthma literature about the intended target population and addressed topics, such as initial asthma diagnosis, interference with quality of life, challenges to optimal asthma management, medication compliance, changes in asthma over time, physician discussions regarding asthma, motivation to participate in an asthma self-management program, and their preferences for asthma education programs. Participants also were invited to share views or any other aspect of asthma management they wished to discuss.

Focus groups were conducted from November to December 2012. As recommended in previous research on the structure of focus groups, each group was designed to consist of 6 to 10 participants. Each focus group lasted approximately 1.5 to 2 hours and was led by 2 facilitators. The 2 facilitators were African American and experienced focus group leaders who had previously worked with African American and asthmatic populations. A physician also was present at the beginning of the focus group to answer questions posed by the participants. Once the question-and-answer period ended, the physician left the discussion area to generate unbiased conversation. The groups were conducted in a manner to ensure confidentiality and encourage spontaneous discussion. The moderators encouraged further discussion, obtained information from less vocal members of the focus groups, and clarified and summarized comments as needed. Each session was recorded and transcribed verbatim by an independent professional transcription service. Participants received a monetary incentive after completion of the focus group.

Analysis

The analysis of the focus group data began with a review of the transcript from the first focus group session. Consistent with recommendations for multiple coding of qualitative research Data, 3 coders from the study team reviewed the first transcript: 2 physicians from the study team who had not been present for the focus group discussions and 1 of the focus group facilitators. Working independently, the coders read the text of the first transcript and identified categories of responses that emerged for each line of text. Then, coders discussed their individual coding of categories and themes. Differences in

coding were resolved with repeated review and discussion of the transcript data. When agreement of consensus was established, a final coding scheme was constructed. This grid of codes was applied to the remaining interview data. Each remaining transcript was reviewed. When new categories or responses were identified, they were added to the grid of codes after consensus was established for the new findings. New categories of responses were added only after all coders had reached agreement. After all transcripts were coded, themes and categories of responses were clustered into major domains. Data are presented as mean \pm SD where appropriate.

HEALTH IT INTERVENTION

Subjects

Potential subjects were recruited who met the following inclusion criteria: age 18 to 30 years; self-identified as African American; accessed email at least three times per week; and had a primary care physician. Participants also had to have uncontrolled persistent asthma, which was defined as currently using a controller medication (inhaled corticosteroids, inhaled corticosteroids plus long-acting beta agonist, cromolyn, or a leukotriene modifier) on a daily basis or using a rescue medication more than 2 times per week. During the eligibility screening interview, potential subjects were asked to rate their asthma control over the past month. If they rated their asthma as "not at all controlled," "poorly controlled," or "somewhat controlled," they were eligible for participation. Those who stated their asthma was "well controlled" or "completely controlled," were excluded from participation, unless they stated that they were using their rescue medication more than 2 times per week. Participants were excluded if they had any other significant cardiopulmonary disease, had a greater than 20 pack-year smoking history (as this level has been associated with the development of chronic obstructive pulmonary disease), and had a significant cognitive impairment that would make participation in the program impossible, or were pregnant at the time of enrollment.

Subjects were recruited from a University asthma clinic as well as two community clinics. Baseline information collected included age, school and employment status, children, history of smoking, age of asthma diagnosis, number and type of asthma medications prescribed, use of peak flow meter or asthma action plan, asthma control and asthma quality of life as measured by the Asthma Control Test (ACT)⁷ and the Mini Asthma Quality of Life Questionnaire (AQLQ) respectively. The study was approved by the University of Michigan Institutional Review Board and all subjects provided written informed consent.

Intervention

The Breathe Michigan program is based on social cognitive theory, which utilizes the principles of self-regulation with support. Social cognitive theory has been well described in the literature and has been used extensively in interventions dealing with human health behavior. The Breathe Michigan program was created and tailored specifically to the challenges facing young, African American adults with asthma. It was completed entirely electronically and therefore, could be done at a time and place convenient to the participant. As the intervention was completed electronically, it required no specialized human support unless initiated by the participant.

Through the Breathe Michigan program, participants were introduced step-by-step to a self-regulatory problem-solving process, specifically designed within their cultural context. The Breathe Michigan program was completed over a period of 6 weeks. Approximately every 3 days, participants were asked to log in to a website and complete a specific assignment. These assignments included choosing problems related to asthma for their situation, identifying barriers to optimal care, and receiving tailored messages of support to overcome barriers. During the program, participants watched 5 educational videos. The videos were produced by the study team exclusively for the Breathe Michigan program and were geared to the communication style and specific concerns of the target population. Young African American adults provided the acting and narration for the videos and assisted with script editing. Each video was 2 – 5 minutes in length.

To facilitate the self-regulation process, participants underwent a 2-week period of self-observation with an online asthma diary. During this period, participants were asked to monitor peak flow measurements twice daily and record the values in their online asthma diary. In addition, they were asked to record asthma symptom triggers and steps used to control the symptoms. After the 2 week period, participants had the option of continuing to record in the asthma diary if they wished.

As part of the program, participants were asked to select two particular problems related to asthma that negatively impacted their life, as well as four specific barriers that made optimal control of asthma difficult for their situation. They were given the option to choose two problems from a list of 13 problems frequently experienced by young, African American asthma patients. For the barrier selection, participants had the option of choosing from among 21 barrier options, again based on previous research. After barrier selection, participants received a tailored message every 3 days describing methods to overcome one of the four barriers selected. Each barrier support message contained one to two paragraphs of information along with relevant links to additional videos and information as appropriate.

If a participant did not log in to the program for over 10 days, a reminder email was sent every three days until the participant logged in and continued advancement through the program. If, after an additional 10 days the participant did not log in despite the reminder emails messages, a reminder phone call was made by an undergraduate student research assistant. This research assistant would simply ask the participant if they had any difficulty accessing the program; verify that they wanted to continue, and to encourage them to log in.

Outcome:

The primary endpoint was the feasibility of a computer-based asthma self-management program, defined as the ability to retain subjects over a 6 week period. A sample size of 40 participants was assessed as adequate for this purpose. Information was gathered from the telephone interview 2 weeks after program completion, at which time participants provided feedback on the Breathe Michigan program. The Mini Asthma Quality of Life Questionnaire (AQLQ), Asthma Control Test (ACT),⁷ and demographic information were also completed through online questionnaires. This information was obtained at baseline, 2 weeks and 3 months post-program completion. Secondary outcomes included the differences in asthma control and asthma quality of life as measured by the ACT and AQLQ respectively at 2 weeks and 3 months post-program completion as compared to baseline. Additional secondary outcomes included use of the online asthma diary for peak flow and symptom tracking.

Results

Thirty-four young adults with asthma participated in the focus groups. All participants were self-identified as African American. The average age of the participants was 24.7 ± 3.3 years, and the average age at which asthma was diagnosed was 7.6 ± 7.4 years. Sixty-eight percent of participants were women and 59% of participants had a high school education or less. Poor asthma control was evidenced by the fact that the mean number of emergency department visits over the past year was 1.5 ± 1.6 , and the mean score on the Asthma Control Test was 16.3 ± 4.1 (range 7e23), which are consistent with "uncontrolled" asthma by the National Asthma Education and Prevention Program guidelines. There were no significant differences in the demographic information or asthma measures among participants from the 3 recruitment sites (data not shown). Six distinct domains emerged from the focus group discussions, which are summarized in Direct quotations from the focus group members are included under each theme to illustrate the richness of the qualitative data.

RESULTS

Focus group findings:

Thirty-four young adults with asthma participated in the focus groups. All participants were self-identified as African American. The average age of the participants was 24.7 ± 3.3 years, and the average age at which asthma was diagnosed was 7.6 ± 7.4 years. Sixty-eight percent of participants were women and 59% of participants had a high school education or less. Poor asthma control was evidenced by the fact that the mean number of emergency department visits over the past year was 1.5 ± 1.6 , and the mean score on the Asthma Control Test was 16.3 ± 4.1 , which are consistent with "uncontrolled" asthma by the National Asthma Education and Prevention Program guidelines. There were no significant differences in the demographic information or asthma measures among participants from the 3 recruitment sites (data not shown). Six distinct domains emerged from the focus group discussions, which are summarized below:

Table 2Major domains identified in focus groups with young African American adults with asthma

| Domain | Descriptors | | | | |
|---|---|--|--|--|--|
| I. Impaired quality of life due to asthma | Unable to pursue desired career choice or had to switch jobs because of asthma symptoms | | | | |
| | Limited ability to play with their children | | | | |
| II. Life responsibilities interfering asthma management | Parenthood or other care-taking roles take precedence over managing their asthma | | | | |
| III. Difficulty with asthma medication compliance and medication concerns | Belief that if they are not having symptoms, the medication is not needed | | | | |
| | Desire not to be different from their peers | | | | |
| | Inconvenient to carry medications | | | | |
| | Costs and lack of insurance are significant barriers | | | | |
| IV. Asthma management has changed as reached young adulthood | Overall increased awareness of their triggers and better informed on how to manage their asthma, even if not necessarily compliant | | | | |
| V. Belief that their physician does not understand their asthma | Believing that their physician was just prescribing medications instead of | | | | |
| management issues | having a discussion with them Believing that physicians were not | | | | |
| | helpful in assisting with obtaining medications | | | | |
| VI. Motivation to participate in an | Convenient and tailored messages are | | | | |
| asthma self-management program | important | | | | |
| | Online programs are desirable | | | | |
| | Programs that utilize smart phones and test messages are also popular | | | | |

Discussion:

Young African American adults represent a population at risk for poor health outcomes because of their minority status and the potentially difficult transition from adolescence to adulthood. The present focus group analysis showed specific quality-of-life limitations because of asthma and barriers to asthma care. The analysis also showed displeasure in physician counseling of asthma in this group. Culturally appropriate discussions between the physician and the patient related to the treatment of chronic disease should increase patients' understanding of their disease and in turn may improve outcomes. In addition, conversations that display the physician's sensitivity to the patient's specific needs are likely to be more motivational to the patient than generic, no tailored discussions. In asthma care, it is crucial to understand the specific barriers of a population to provide the most appropriate and effective care.

Health IT program findings:

Results:

A total of 118 potential subjects were contacted. Of those contacted, 28 declined participation and an additional 46 potential subjects expressed interest, but were ineligible. The most common reason for ineligibility was well-controlled asthma (76%). A total of 44 participants were enrolled. One participant withdrew and 7 were lost to follow up. Thirty six participants (82%) completed the program and completed the 2-week post-program online evaluation. Thirty four participants (77%) completed the 3 month post-program evaluation (Figure 1). Of the 44 subjects who enrolled in the program, 24 (54.5%) required at least one reminder phone call for lapses in participation.

Baseline characteristics are shown in table 1. All participants self-identified as African American. The average age of participants was 24.7 +/- 3.6 years, and the average age of asthma diagnosis was 7.4 +/- 6.9 years. A busy lifestyle was evidenced by the percentage of subjects currently in school (43%), currently working (59%), married (16%), and being parents (36%). Poor asthma control and poor asthma quality of life was demonstrated by a mean score on the ACT of 16.2 +/- 4.0, consistent with "uncontrolled" asthma by the National Asthma Education and Prevention Program guidelines¹¹ and a mean AQLQ score of 4.1 +/- 1.3. Subjects also reported difficultly in reaching their healthcare providers to discuss their asthma care (46%), decreased satisfaction with their asthma medical care (32%), and a perception that their asthma medications were only somewhat effective in achieving asthma control (43%) (data not shown). Baseline characteristics were compared between the 34 subjects who completed the program and the 10 subjects who withdrew or were lost to follow up and no significant differences were found (data not shown).

During the course of the program, participants were asked to choose 2 problems to address regarding their asthma as well as 4 barriers that they felt negatively affected their asthma control. The five most commonly selected problems and the five most common barriers to optimal asthma management chosen are listed in Tables 2 and 3, respectively.

Qualitative comments about the program

At the telephone interview conducted 2 weeks post-program completion, participants provided qualitative comments regarding their experiences with the program. All 34 participants (100%) who completed the 2-week post-intervention phone survey found the program to be helpful, and all but one (97%) would recommend it to others. Many participants noted that the program was helpful for increasing their asthma acceptance and overall knowledge. One representative comment was: "I was in denial about my asthma diagnosis, and this helped me accept it."

The educational videos were cited most often as the favorite aspect of the program (Table 3), which may have been due to the fact that the actors in the videos were of the same age and race as the participants, making the videos more relatable. One participant noted: "The videos definitely made me a lot more aware about my asthma and the different types of symptoms to look for". Another participant stated, "The videos were well done and gave me a lot of insight into my asthma."

Another popular aspect of the program was the tailored messages with advice on how to overcome the specific barriers to optimal asthma management. Representative comments included: "I liked how I was able to choose the things that were affecting my asthma in particular."

Many participants (74%) reported finding the online asthma diary to be helpful. When referring to the online asthma diary, one participant responded: "Being in this program made me want to monitor my asthma more...it made me look at it differently."

While the program was highly rated overall, there were some suggestions for improvements. Some participants noted forgetting to log into the program or to check their peak flow values due to responsibilities at school and work and generally being too busy. One participant suggested that integrating text message reminders into the program would provide a helpful reminder to continue to log in regularly. At least 35% of participants used their smartphones to view the videos and/or log in to the program, and many participants suggested optimizing the program for smartphone-use.

Secondary Outcomes:

Secondary outcomes included improvement in asthma control and asthma quality of life as measured by the ACT and AQLQ respectively at baseline, 2 weeks and 3 months post program completion. As shown in Figure 2, the average ACT score increased significantly from 16.3+/-4.2 to 19.0 +/-4.7 (p < 0.001), taking the ACT score from the uncontrolled to the controlled range. The improvement was sustained as the average ACT score 3 months post-program remained in the controlled range at 19.4 +/-3.6 and was also significantly improved from baseline (p < 0.001). The improvement of over 3 points is greater than the minimally important difference on the ACT.

The mean AQLQ score at baseline was 4.1 +/-1.3, which significantly increased to 5.1 +/- 1.2 at 2 weeks post-program completion (p < 0.001). As with the ACT, the increase in AQLQ score was sustained at 3 months post-program completion with an average score of 5.2 +/- 1.3 (p<0.001), which was also significantly increased from baseline (Figure 3). This increase was also greater than the minimally clinically important difference of 0.5 for AQLQ scores. The intervention worked well for both severe and non-severe asthmatics. Severe asthmatics (those requiring > 1 controller medication) and non-severe asthmatics, both showed a statistically significant increase in ACT and AQLQ scores at 2 weeks and 3 months post-program completion compared to baseline (Supplemental table 1).

Overall, use of the online asthma dairy was also successful. Thirty-five participants (79.5%) utilized the diary at least once to record peak flow values, asthma symptoms, asthma triggers, or medications used. Subjects who did and did not use the online diary achieved improvement in the ACT score. However, only those subjects who used the asthma diary had improvement in the AQLQ score at both the 2 week and 3 month endpoints (Supplemental table 2).

Discussion

Minority populations in the United States have significantly worse health outcomes in asthma. It is therefore essential to implement appropriate solutions to decrease healthcare disparities. Young, African American adults are a group at risk for poor health outcomes due to both their minority status and age. This age group may have difficulties with access to asthma care due to competing responsibilities including: lack of financial resources, child care duties, work responsibilities, school, and role of caretaker for other family members, inadequate insurance coverage, and household chores. Because of these responsibilities, young adults may be less likely to attend in-person asthma management and behavioral education sessions. In addition, lack of tailored and culturally relevant programs may also disenfranchise minority populations from optimizing their asthma care. Original self-management programs must therefore be developed. An asthma self-regulation intervention that can be delivered electronically allows the program to be personalized to the subject's time, interest and priorities.

A careful review of the literature reveals that among minority populations with asthma, only 11 randomized controlled trials using different forms of electronic media have been reported. All but one of the previously reported studies was conducted in children or adolescents, and the study performed in adults was not successful. The duration of these studies ranged from 1 month to 1 year and nearly all required special staffing (i.e. nurses, asthma counselors, or asthma coaches) for completion. Unfortunately, in urban areas with limited resources, this is often not possible. In addition, staff turnover, temperament, and training can result in varying degrees of program fidelity and participant commitment. The design of the Breathe Michigan program ensures that content will be reproducible in any setting, without the requirement for special staffing. While 54.5% of the participants did require a phone call, this was done by an undergraduate student who did not have any asthma education training or knowledge.

Overall, the Breathe Michigan program was shown to be feasible as evidenced by the percentage of participants who completed the program (82%) and were available for follow-up at 3 months post-intervention (77%). Previous studies among young African American adults have found retention and completion rates of 36% at 3 months post-intervention, 63% during a 6 week trial, and 75% at 1 month post-intervention (though much lower among those under 25 years of age). While these trials were not conducted in asthmatic patients, they do highlight retention difficulties in this target population. One study found that young African-American adults felt time commitment was the greatest impediment to participation in research trials. The Breathe

Michigan program was completed entirely electronically, allowing the program to be done at any time and place convenient to the participant, which likely augmented our completion and retention rates.

Of those who completed the program, 100% found the program to be helpful and 97% would recommend it to others. The educational videos were cited most often as the participants' favorite aspect of the program, in part because they were designed to specifically address the concerns of young African American adults and also utilized models of color, allowing the participants to relate to the video content. Additionally, the videos were brief (all less than 5 minutes) which made it more likely that the participants could watch each video in its entirety without losing interest. The Breathe Michigan program was efficacious with statistically significant and clinically meaningful improvements in ACT and AQLQ from baseline to 2-weeks and baseline to 3-months post program completion (Figures 2 and 3). Although this is an uncontrolled pilot study, the short-term results are promising, and deserve further investigation.

In conclusion, the Breathe Michigan program is a well-received online asthma education program tailored to the needs and preferences of young, African American adults with asthma. The program proved to be both feasible and successful, and was able to improve asthma control and asthma quality of life (albeit in an uncontrolled trial). Further investigations should examine whether such a program can lead to long-term improved outcomes and potentially decrease health care disparities.

Table 1: Baseline Subject Characteristics, n=44

| Clinical Characteristics | | | | | | | |
|---|--|-------------|--|--|--|--|--|
| Age (y), mean (SD) | 24.7 (3.6) | | | | | | |
| African American Race, n | 44 (100) | | | | | | |
| Gender, female, n (%) | 34 (77) | | | | | | |
| Currently in school, n (%) | | 19 (43) | | | | | |
| Currently working, n (%) | | 26 (59) | | | | | |
| Hours worked per week (fo | or those currently working), mean (SD) | 31.5 (12.2) | | | | | |
| Currently Married, n (%) | | 7 (16) | | | | | |
| Parent, n (%) | | 16 (36) | | | | | |
| Current Smoker, n (%) | | 9 (21) | | | | | |
| Former Smoker, n (%) | 6 (14) | | | | | | |
| Currently living with a smo | 15 (34) | | | | | | |
| Age at asthma diagnosis (| 7.4 (6.9) | | | | | | |
| Asthma Medications, n (%) | | | | | | | |
| | Rescue medication only | 12 (27) | | | | | |
| | Monotherapy controller | 14 (32) | | | | | |
| | ICS+1 additional controller | 13 (30) | | | | | |
| | ICS+>/=2additional controllers | 5 (11) | | | | | |
| Own a peak flow meter, n | 27 (61) | | | | | | |
| Have a written asthma acti | 20 (45) | | | | | | |
| Unscheduled office visits in previous year due to asthma, mean (SD) 1.6 (1.6) | | | | | | | |
| ED visits in previous year due to asthma, mean (SD) 1.1 (1.4) | | | | | | | |

Abbreviations: ED, emergency department; ICS, inhaled corticosteroid.

Table 2: Most commonly selected problems related to asthma

| Problems (n=43 respondents) | Frequency Cited, n(%) |
|---|-----------------------|
| My asthma is unpredictable | 19 (44.0) |
| Asthma limits things in my life I'd like to do | 17 (39.5) |
| Have to use my albuterol inhaler a lot | 12 (28.0) |
| Have frequent asthma symptoms, wish they would stop | 11 (25.6) |
| My asthma makes it hard to sleep | 9 (20.9) |
| Hard to do sports because of my asthma | 9 (20.9) |

Table 3: Most commonly selected barriers related to optimal asthma control

| Barriers (n=39 respondents) | Frequency Cited, n(%) |
|---|-----------------------|
| Season/weather changes make my asthma flare up | 29 (74.4) |
| Have lots of responsibilities, forget to take care of my asthma | 17 (43.6) |
| Forget to take my asthma medications regularly | 13 (33.3) |
| Exercise causes asthma to act up | 12 (30.8) |
| Do not feel I need to take my asthma medications every day | 11 (28.2) |

Table 4: Program features stated as very helpful

| Feature | Responses, n (%) |
|---|------------------|
| Video (general category) | 21 (61.8) |
| Tailored suggestions for overcoming asthma barriers | 14 (41.2) |
| Online asthma diary | 6 (17.6) |
| Receiving a peak flow meter | 5 (14.7) |

Figure Legends

Figure 1: Subject outcomes

Figure 2: Asthma Control Test score at baseline, 2 weeks, and 3 months post-program completion. Data presented as mean+/- SEM. *P < 0.001

Figure 3: Mini Asthma Quality of Life Questionnaire (AQLQ) score at baseline, 2 weeks, and 3 months post-program completion. Data presented as mean +/- SEM. * P < 0.001

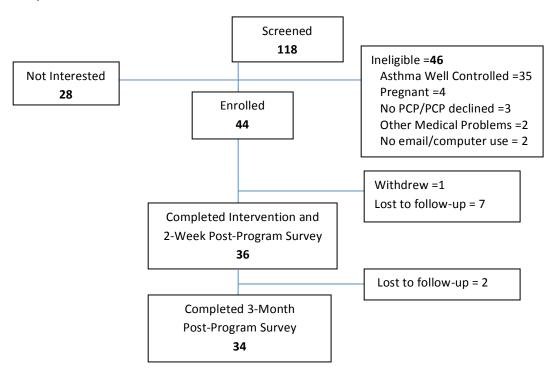


Figure 2

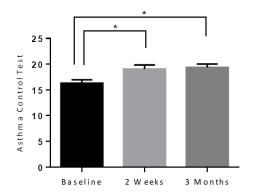
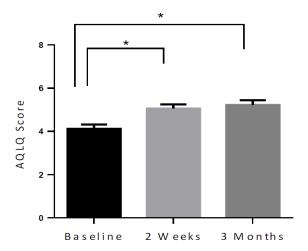


Figure 3



Supplemental Table 1. AQLQ and ACT Score Summary by asthma severity

| | | Baseline | 2 Weeks | | | | 3 Months | | | | |
|---|----|----------|---------|----|-------|-----|-------------|----|-------|-----|---------|
| | N | Mean | SD | N | Mean | SD | P value | N | Mean | SD | P value |
| Asthma Quality of Life Questionnaire (AQLQ) Score | | | | | | | | | | | |
| Overall | 44 | 4.12 | 1.3 | 36 | 5.05 | 1.2 | <0.000 1 | 34 | 5.22 | 1.3 | <0.0001 |
| Severe Asthmatics* | 18 | 4.54 | 1.2 | 14 | 5.13 | 1.3 | 0.0295 | 13 | 5.50 | 1.3 | 0.0033 |
| Non-Severe Asthmatics | 26 | 3.83 | 1.4 | 22 | 5.00 | 1.2 | <0.000 1 | 21 | 5.05 | 1.3 | <0.0001 |
| Asthma Control Test (ACT) Score | | | | | | | | | | | |
| Overall | 41 | 16.29 | 4.2 | 32 | 19.03 | 4.7 | <0.000 1 | 31 | 19.35 | 3.6 | <0.0001 |
| Severe Asthmatics | 16 | 17.31 | 4.0 | 13 | 18.31 | 4.9 | 0.0120 | 12 | 19.92 | 3.4 | 0.0119 |
| Non-Severe Asthmatics | 25 | 15.64 | 4.3 | 19 | 19.53 | 4.5 | 0.0002 | 19 | 19.00 | 3.8 | 0.0009 |

^{*}Severe: Prescribed an inhaled corticosteroid and at least one other controller medication at baseline. Non-severe: Prescribed albuterol only or a monotherapy controller medication at baseline

Supplemental Table 2. AQLQ and ACT Score Summary by diary usage

| | | Baseline | 2 Weeks | | | | 3 Months | | | | |
|---|----|----------|---------|----|-------|-----|-------------|----|-------|-----|---------|
| | N | Mean | SD | N | Mean | SD | P value | N | Mean | SD | P value |
| Asthma Quality of Life Questionnaire (AQLQ) Score | | | | | | | | | | | |
| Overall | 44 | 4.12 | 1.3 | 36 | 5.05 | 1.2 | <0.000 1 | 34 | 5.22 | 1.3 | <0.0001 |
| Never used diary | 9 | 4.36 | 1.0 | 5 | 5.15 | 1.1 | 0.0261 | 5 | 4.43 | 0.7 | 0.0275 |
| Used diary at least once | 35 | 4.06 | 1.4 | 31 | 5.04 | 1.3 | <0.000 1 | 29 | 5.36 | 1.3 | <0.0001 |
| Asthma Control Test (ACT) Score | | | | | | | | | | | |
| Overall | 41 | 16.29 | 4.2 | 32 | 19.03 | 4.7 | <0.000 1 | 31 | 19.35 | 3.6 | <0.0001 |
| Never used diary | 9 | 16.44 | 4.8 | 5 | 18.80 | 4.8 | 0.2278 | 5 | 18.20 | 4.0 | 0.1748 |
| Used diary at least once | 32 | 16.25 | 4.1 | 27 | 19.07 | 4.7 | <0.000 1 | 26 | 19.58 | 3.6 | <0.0001 |

Publications:

Speck AL, Nelson B, Jefferson SO, Baptist AP. Young, African American Adults with Asthma: What Matters to Them? Ann Allergy Asthma Immunol. 2014 Jan;112(1):35-9

Submitted:

An electronic asthma self-management intervention for young African American adults. Submitted to JACI: In Practice on 4/1/2015 (Decision pending)

Abstract publications/Oral presentations

Speck AL, Nelson B, Jefferson SO, Baptist AP. Young, African American Adults with Asthma: What Matters to Them? J Allergy Clin Immunol. 2014: 133(2):AB73

Couch CE, Speck AL, Baptist AP. Electronic Asthma Self-Management Program Can Improve Asthma Control and Quality of Life in Young, African Americans. J Allergy Clin Immunol. 2015: 135(2):AB79

In preparation:

Baptist AP, Islam N, Joseph CL. A systematic review of health information technology for African Americans with asthma